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ABSTRACT

This newsletter issue is devoted to summaries of 12 papers on culture and disability issues in the Pacific. The summaries presented span Oceania and are based on papers representing Polynesia, Micronesia, and Melanesia. Papers have the following titles and authors: "Nstasinge: The Sickness of a Small Boy from the Finisterre Range in Papua New Guinea from an Emic (Anthropological) and Etic (Biomedical) Perspective" (Verena Keck); "Culture and Disability in Palau" (Yoichi K. Rengiil and Jane E. Jarrow); "Perceptions of Physical, Mental, and Sensory Disabilities on Woleai and Lamotrek, Carolina Islands" (William H. Alkire); "The Place of Disabled Persons in Rotuman Society" (Jan Rensel and Alan Howard); "The Connection of Ability and Disability on a Subsistence Atoll" (Patrick O'Brien); "Disability in the Western Pacific: Perspectives from Guam" (Rebecca A. Stephenson); "Disability and Rehabilitation in Cross-Cultural Perspective: A View from New Zealand" (Robert J. Gregory); "Diabetes Management: A Polynesian Perspective" (Judith C. Barker). Concluding comments by Linda S. Mitteness emphasize that in a small-scale society, the individual might occupy many productive social roles so that a physical or mental impairment that interferes with one of those roles may not be as devastating as in a large-scale, money economy where employment is the primary source of a person's value. (JDD)

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UNIVERSITY OF NEW HAMPSHIRE | SPECIAL ISSUE | JANUARY 1993

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Culture and Disability in the Pacific

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UNIVERSITY OF NEW HAMPSHIRE **SPECIAL ISSUE** JANUARY 1993

Culture and Disability in the Pacific

A conversation at the 1991 meeting of the Society for Disability Studies in Oakland, California with Maureen Fitzgerald , an anthropologist, and staff member of the Rehabilitation Research and Training Center on the Pacific in Honolulu, led to the piece which follows. In our conversation, Dr. Fitzgerald described the work of the Association for Social Anthropology in Oceania (ASAO). The approach of the ASAO sounded as if it fit IEEIR objectives. Although the ASAO sessions deal with Pacific Island societies, the organizers and participants see the information as a contribution to general anthropological and disability-related theory. They also share a sincere concern that the information have an applied focus and contribute to the development of culturally aware and sensitive service providers and service programs. Therefore, Fitzgerald and a colleague (and IEEIR Fellow), Jocelyn Armstrong, were encouraged to develop the material for this issue of the Interchange. (Editor's Note)

Introduction

There is a growing recognition of the importance of culture in understanding disability-related issues and the importance of considering cultural issues in the development and provision of habilitation and rehabilitation services. The rhetoric of cultural sensitivity is easy; the application much more difficult, especially without the primary tool kit—cultural knowledge.

The 1991,1992 and 1993 annual meetings of the Association for Social Anthropology in Oceania (ASAO) are providing a forum for contributions to this tool kit of cultural knowledge in a series of informal, working, and formal sessions entitled "Culture and Disability in the Pacific." This issue of the *Interchange* is devoted to summaries of papers prepared for the 1992 working session held in New Orleans, Louisiana, USA, in February. Twelve papers, representing the contributions of fifteen people, were presented. The contributors represent a range of disciplinary backgrounds in addition to anthropology and work in an international variety of academic and applied settings.

The sessions are organized by Maureen Fitzgerald and Jocelyn Armstrong. They were motivated by reviews of the literature which revealed little information on issues related to disability and rehabilitation in the islands of the Pacific. Considering the

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vast area involved, the number of societies, and the amount of anthropological and related work in the area, the lack of published information was striking. Was there an untapped wealth of knowledge among the membership of ASAO? It seemed likely that while few people went into the field for the specific purpose of collecting disability-related information, the length of time spent in the field and the anthropological approach of wholistic observation and data collection must have generated considerable relevant information.

An exploratory informal session was convened at the 1991 ASAO meetings in Victoria, British Columbia. The purpose was to assess the potential for contributions of cultural knowledge on disability in the Pacific and to develop a set of topics the group might address. By the end of that first meeting it was clear that ASAO members did have important information to share and a number of significant topics were identified. They include: Pacific islander definitions of disability, attitudes towards disabilities and people with disabilities, family responses, the myths and realities of societal responses to disabled members, the effect of modernization on the disability experience, the epidemiology of disabilities, culturally sensitive rehabilitation program development, and traditional adaptations to disability. The opening paper of the 1992 session by **Maureen Fitzgerald** formulated these issues as questions to be addressed. **Jocelyn Armstrong** contributed a preliminary review and analysis of existing literature on the topics.

Linda Mitteness, the discussant, identified other recurring themes and additional issues worth developing. For the 1993 formal symposium, which will convene in Kona, Hawaii, in March, participants are developing or refining their papers with all of these themes and issues in mind. The overarching theme of the symposium will continue to be perceptions and attitudes towards disability and more attention will be given to epidemiological perspectives, contextualization of case material, and disability in relation to power, productivity and personhood.

The summaries presented here span Oceania and are based on papers representing Polynesia, Micronesia, and Melanesia. **Mac Marshall's** paper contributed to the ethnographic database on disabilities by providing case material from a small Micronesian atoll. **Joakim Peter's** provocative paper which included some personal case material, looked at the use of humor by a group of Micronesian islanders as part of a reintegration process. The summaries that follow raise many interesting and important issues.

Verena Keck's summary, based on work in Papua New Guinea, draws attention to the importance of the emic (insider) perspective and how many disability issues are grounded in people's theories of illness. Her concerns about using a Western and medical frame of reference are echoed by other contributors.

An exploration of the language of disability in Palau (Micronesia) by **Yoichi Rengiil** and **Jane Jarrow** provides a context in which to examine perceptions and classifications of disability. The problems of using a Western frame of reference are again emphasized.

William Alkire, using other data from Micronesia, looks at how different types of disabilities, coupled with beliefs about causation, affect things like rank, power, and prestige.

Jan Rensel and **Alan Howard**, in talking about Polynesian Rotuma, place our considerations clearly in the domain of social relationships, values, roles, personhood, and productivity. Impairments are only one of the many personal characteristics and cultural principles which define roles, status, and relationships.

The summaries presented here span Oceania and are based on papers representing Polynesia, Micronesia, and Melanesia.

Patrick O'Brien's presentation of a Micronesian atoll community further reinforces the critical importance of interrelationships in small communities.

Rebecca Stephenson, in a report from Guam, reminds us of the diversity of Pacific island societies: they are not all rural, nor are they isolated from the rest of the world. For better or for worse, the Western developed world with its rules and perspectives is juxtaposed with the Pacific islander perspective, a point also brought out in **Robert Gregory's** views from New Zealand.

Judith Barker, by focusing on one potentially disabling condition, reinforces many of these points and reminds us of the issue of change and cultural and biological responses to change.

Linda Mitteness' summary of her discussion highlights some of the important issues raised during the presentation of these papers. Clearly, as Gregory points out, our understanding of disabilities and people with disabilities is enriched by cross-cultural explorations.

❖ *Nstasinge: The Sickness of a Small Boy from the Finisterre Range in Papua New Guinea from an Emic (Anthropological) and Etic (Biomedical) Perspective*

Verena Keck, University of Basel, Switzerland

Anthropologists generally agree that judgments of being ill or well are culturally defined, closely connected to the view each culture takes of life, to values and to concepts of personhood. They also agree that for many (perhaps most) Pacific societies illness is not a biological accident of the body, but has been caused by something or somebody and finding out the causes of an illness is a matter of central interest.

In my studies of Yupno society in Papua New Guinea, it struck me how little some previous researchers, especially those with dual professions as anthropologist and physician, were able to deviate from the biomedical frame of reference. In order to avoid the dilemma of mingling biomedical interpretations of disease and traditional models of explaining illness, I made the common anthropological distinction between the two aspects of a sickness and subdivided "sickness" into "disease" and "illness." Whereas the term "disease" belongs to the biomedical model and refers to dysfunctions and abnormalities in organs and organ systems, "illness" refers to the culturally defined perceptions and experiences of the patient and his/her social group.

To do justice to a representation of the Yupno medical system and to avoid the unfortunate mixing of emic (insider) and etic (outsider) views, I chose a method involving interdisciplinary cooperation with physicians. The physicians examined the physical condition of the Yupno from the biomedical (etic) point of view; I dedicated myself to the complex "illness" by taking the Yupno (emic) point of view. As an anthropologist and non-physician, it was easier for me to concentrate on the Yupno concept of illness. I illustrate this interdisciplinary cooperation with reference to the case history of a small boy named Nstasinge.

The Yupno classify illnesses according to their presumed causes. Physical symptoms are recognized and named, yet they are assigned very little importance. These symptoms are not considered as belonging to an illness. Illness only starts when these "ailments" have been caused by something. The diagnostic aim is, therefore, to find out about these causes. The important questions are not what a person is ill of but why he/she is ill and who is responsible for it. They are looking for answers to these questions because, for them, causes of illness are primarily socially defined, be it that the sick person had misbehaved or that another person voluntarily made somebody sick out of rage or anger. The cause (why) and the person responsible for it (who) appear in culturally significant "signs" and dreams, are discussed in meetings, or can be identified by various techniques of "finding out."

The Yupno way of coping with illness, establishing a diagnosis and deciding on a therapy, becomes obvious in the interpretation of Nstasinge's sickness episode as reconstructed from his mother's account, from a long discussion at a meeting and from conversations with informants. These sources started by assuming a minor ailment and then progressed to the worst case-level and its cause by the method of trial and error. They moved from believing the child had a "natural disorder," where he was "hot" but not yet "ill," through believing he was ill from "oppressing problems," as a result of a lapse in someone's behavior, to the idea that the child's "free soul" had been frightened from his body by the actions of another person.

I agree with the view that beliefs, perceptions, and attitudes concerning disability are a "forgotten theme" in anthropology. However, I do not think we can produce very culture-adequate results by taking "disabilities," a Western concept, as an "independent" category for research.

The same sickness episode, seen from the point of view of Western medicine, reconstructed from conversations with personnel of the health center and from interpretations of the hospital record by a physician, can be presented as follows. The diagnoses included: meningo-encephalitis, brain damage following meningitis, questionable tuberculosis and pneumonia.

I met the child again during a later visit in the village. In the case of Nstasinge, both kinds of treatment, the traditional as well as the biomedical, had failed. The little boy was two years old and mentally and physically handicapped as a result of his sickness. This, too, can be interpreted in different ways.

The Yupno deliberations on little Nstasinge's sickness made it clear how differently (compared to the representatives of biomedicine) they conceive the field of "sickness," how

heavily it is marked through their "hot-cool-cold" concept and their idea of personhood. By purposely not correlating the Yupno concept of illness with biomedical classifications but presenting the emic as well as the etic way of explaining sickness, as two independent non-contiguous models, the Yupno frame of interpretation can be demonstrated more adequately. It was also possible to avoid describing a native medical system with the biomedical system as the basis of reference and evaluation.

I agree with the view that beliefs, perceptions, and attitudes concerning disability are a "forgotten theme" in anthropology. However, I do not think we can produce very culture-adequate results by taking "disabilities," a Western concept, as an "independent" category for research. The division of bodily, mental or psychic disabilities is also a Western division, grounded in Western concepts of personhood. I also think that our research cannot be separated from the whole complex "illness" because disabilities are, in most cases, a result of illness.

❖ Culture and Disability in Palau

Yoichi K. Rengiil, University of Guam
Jane E. Jarrow, Association on Higher Education and Disability, Columbus, Ohio

When so much of culture is embodied in language, it is important to include a study of language in any cultural analysis of disability issues... At the same time, however, it is important to distinguish between how people with disabilities are perceived and how they are treated.

When so much of culture is embodied in language, it is important to include a study of language in any cultural analysis of disability issues. This paper reviews terminology employed in Palau in Micronesia to refer to persons with disabilities and discusses cultural and conceptual meanings behind the literal translations of these terms. At the same time, however, it is important to distinguish between how people with disabilities are perceived and how they are treated.

There is no real translation of the English-language phrase "people with disabilities" (as used in the U.S. today) into the language (or culture) of Palau. The wide variety of conditions/limitations implied by the term "disability" in English is not seen as a single entity. People with physical disabilities are distinct from people with mental disabilities, who are distinct from people with sensory disabilities. People with chronic health impairments are not seen as belonging to, or associated with, any of these three groups. There is nothing that can be said or assumed about "people with disabilities" that applies to all the people who have what Western society considers to be a disability. If there is a generic term, it would be *ngodech*, a word referring to the state of being different. There is a generic understanding of someone who has a physical, mental, or sensory disability as being different. However, It does not convey any belief in common etiology, potential, future, or associated stigma or handicap. It is used as a descriptor (such as "blond" or "freckled") but not as a means of identifying or placing a person within the society.

The language of Palau has specific terms to identify some disabilities, others are referred to with a more generic nomenclature. Someone who is blind is *mikeu*; someone who is deaf is *mechaud*; an amputee is *chelmus*. These words appear to mean (convey) no more or less than their English equivalents, except that they are used to describe the person as well as the condition (used as nouns as well as adjectives). By contrast, there are generalized terms to describe persons with physical disabilities from cerebral palsy affecting mobility, to paraplegia and quadriplegia, including *chitut* (weak or incapable) and *sechudel* (part of the individual does not work right) from the root *selchudel*, meaning "in the process of being crippled." In traditional usage, someone who is mentally retarded is called *ultechei* which, roughly translated, means "substitute" or "replacement." The concept conveyed is that this is not a true person, but rather a less-than-fully-human entity. This concept ties the ability to think to being a sentient being. People with other mental disabilities (psychiatric or emotional disabilities) are also traditionally discounted in the culture of Palau; the words *kebelung* ("crazy"), and *tedobech* ("half") are used to describe anyone whose behavior is outside the range of the socially accepted. While such individuals are clothed, fed and maintained within the kinship system, they are considered a burden on the family and the community and their presence is unwelcomed.

In Palau, as in Western society, there is a tendency to judge the severity of disability by the amount of loss experienced, while judging the severity of handicap on the amount of function remaining.

Westerners can speak of someone with a "mild hearing loss" or a "severe visual impairment" and believe that the higher the spinal cord injury, the more severe the disability because more sensation and movement or control is lost. The people of Palau do not have terminology to express these distinctions, although the concept of relative loss is recognized.

The type of disability can influence the perception of handicap as a function of perceived normal roles. Westerners consider someone with a visual processing problem that makes reading impossible to be more severely handicapped than someone with a visual-motor perception problem that occasionally causes him/her to trip or overreach an object. The language of Palau is not taught as a written language. An inability to read may pose no handicap, while the inability to accurately cast your fishing line or maintain your footing on rough terrain may create a very real handicap in fulfilling social roles and expectations. At the same time, the severity of the handicap may not be judged by the severity of the disability. A man who is missing one arm but can independently do all the things required of an adult (fishing, manipulating tools, hunting, dressing, eating, and so on) may not be considered handicapped by this "severe" disability (total loss of ability to perform tasks in a typical manner).

Western views of disability limit exploration of causation to the medical model, searching to establish only the point at which the nerve is damaged, the spinal cord is broken, or the means by which the germ entered the system. In Palau, the question of what caused a disability is of primary importance—not the medical cause, but the spiritual cause. All disabilities are believed to be caused by some failure on the part of someone to follow a tradition, fulfil a responsibility, appease an ancestor, or the like. There is an understanding that disabilities are caused by someone's actions (an element of blame is attached), but that someone is not necessarily the individual who is disabled. A child born with a disability is the recipient of a punishment assigned to a parent or kinsman, or the result of a failure on the part of the family to meet the obligations to one another or to the community. Even acquired disabilities are believed to be a function of some action, or lack of action, having to do with spiritual responsibilities. The accident that caused a break in the spinal cord resulting in paraplegia is brought about by some "higher authority" in order to punish.

This focus on cause rather than effect has positive implications for pursuing the Western policies of rehabilitation and equalization of opportunities in Palau. Palauans do not deny the Western medical model, they simply believe that the reasons behind medically-related phenomena can be assigned to spiritual, rather than earthly, causes. However, the introduction of the concepts and practices of rehabilitation and equalization of opportunity do not interfere in any way with native beliefs regarding the existence of disability. Palauans do not believe that a person with a disability is necessarily personally guilty or wrong; correction of the mistake absolves the responsibility for creating the disability. Thus objections to any activity which can be seen to minimize the long term impact of the disability are unlikely.

Western views of disability limit exploration of causation to the medical model, searching to establish only the point at which the nerve is damaged, the spinal cord is broken...

❖ *Perceptions of Physical, Mental, and Sensory Disabilities on Woleai and Lamotrek, Caroline Islands*

William H. Alkire, University of Victoria, Canada

Within the coral islands' societies of the central and western Carolines an individual's rank, power, and prestige derive from a "package" of variables, the most important of which are: genealogy (and its concomitant, control of land), gender, and personal ability and expertise. These measures of rank, in fact, have wide currency throughout the Austronesian-speaking world, an area that spans from Southeast Asia to Easter Island. It follows, with respect to the personal ability and expertise measures, that disabilities would therefore have great potential for affecting rank and prestige. Data collected on Woleai, Lamotrek and related islands in the central Carolines support this supposition, but they also emphasize that members of these cultures appear to reach their conclusions regarding this issue based on two local theories. The first is a general theory of disease, which holds spirits responsible; and the second a theory of intelligence and sentience, that links these abilities closely to

hearing and speaking.

Physical (mobility) disabilities rarely, in and of themselves, fundamentally alter rank or prestige if the individual so disabled attempts to participate and contribute to village life and if the spirits involved are malevolent ones. Mental (psychosis, senility) disabilities do affect one's standing, but not always negatively. The ghosts or spirits assumed responsible may be respected or feared. The person may only loose status if his or her behavior is antisocial. Sensory disabilities (deafness, inability to speak) can result in a more consistent loss of prestige because vengeful ancestral spirits often attack one's intelligence and expertise (an important measure of prestige) through these closely related senses.

❖ *The Place of Disabled Persons in Rotuman Society*

Jan Rensel University of Hawaii, Honolulu
Alan Howard, University of Hawaii, Honolulu

The island of Rotuma is located approximately 300 miles north of Fiji. As in most other Pacific Island communities, personal relationships are based upon a combination of kinship, co-occupation of villages or hamlets, and participation in common activities. Individuals relate to one another as total persons, based upon known personal histories. The Rotuman language has an extremely limited vocabulary for dealing with disabilities, suggesting that they are not a focus for cultural attention. While physical or mental impairments may influence specific relationships, there are no well-developed roles for disabled persons as such; that is, specific disabilities do not dictate social expectations to any great degree. An impairment or disability is one consideration among many in each relationship, and much depends upon the way an individual is situated in a household, community and network of kin. It follows from this that no strong socialization pressures are exerted to induce an impaired individual to conform to specific role expectations for a blind person, hunchback, etc. Therefore, individual attitudes, abilities and dispositions play a correspondingly greater part in structuring a person's role within households and communities, than do particular impairments or disabilities.

What matters on Rotuma is the way in which an impairment relates to key cultural principles, such as immanent justice, prescriptive generosity, personal autonomy, balanced exchange and family honor.

What matters on Rotuma is the way in which an impairment relates to key cultural principles, such as immanent justice, prescriptive generosity, personal autonomy, balanced exchange and family honor. We regard these principles as part of a broad pool that individuals may choose to employ or disregard, according to circumstances and personal agendas. Indeed, a person who is neither physically nor mentally impaired may be socially handicapped by other circumstances in terms of these principles. In our opinion, therefore, perceptions of and attitudes and behavior toward, disabled persons on Rotuma are better understood as the products of negotiation rather than the imposition of cultural scripts.

Rotuman explanations for ill-fortune often presuppose it to be a punishment for moral transgressions. Thus it is common for individuals to dredge up past events or conflicts to account for deaths, serious accidents or illnesses, political and financial setbacks. While short-term illnesses and minor accidents may be accounted for in naturalistic terms, persistent conditions and permanent impairments lend themselves to explanations based on immanent justice. Belief in immanent justice can affect a person with a disability in two important ways. On the one hand, it grants license for others to place the person in a morally inferior position, and thus justifies pariah treatment. It is important to point out that such attribution is by no means automatic; much depends upon the history of previous relationships and current dispositions. Thus some people may resort to claims of immanent justice when it suits them, while others may ignore it altogether. On the other hand, mistreatment of disadvantaged persons is itself a moral transgression, and can lead to affliction of unkind individuals. Using this reasoning, people sometimes explain an acquired disability as a consequence of mistreating someone who had that same condition.

The willingness of households to accommodate members with disabilities as individuals can be attributed, in part, to the importance placed on generosity in Rotuman culture. Persons who are well-off are expected to give amiably to those who are less fortunate. In return they are praised for their kindness, or at least are able to avoid criticism for being stingy and hard-hearted. There are limits, however, since relationships are expected to balance over time. Exchanges may involve labor,

food, political support, money or other valuables in various combinations, but to be considered a fully competent person requires giving as much as one receives. The social situation of people with disabilities persons therefore largely depends on how their impairment affects their ability to produce food, earn money and work in productive ways.

A principle of autonomy operates at every level of Rotuman society. Not only do individuals exercise autonomy within their households and communities, but villages are autonomous vis-a-vis one another, and each of the island's seven districts operates as an independent political unit. Respect for others' willfulness means that persons who are disabled are given a strong negotiating voice in determining their social existence. They are generally permitted to participate in whatever activities they feel up to, and are not systematically discouraged from involvement. Alternatively, if they decide not to participate in communal activities, little effort is made to reintegrate them until they give clear signs of their willingness to return to the fold.

Overall, our data suggest that the treatment of persons with disabilities on Rotuma is less the consequence of a prescribed set of norms, based on notions of what such individuals can or cannot do, than the result of negotiated interactions that derive from total social histories.

Overall, our data suggest that the treatment of persons with disabilities on Rotuma is less the consequence of a prescribed set of norms, based on notions of what such individuals can or cannot do, than the result of negotiated interactions that derive from total social histories. This means that impairments that occur later in life are less likely to require dramatic role shifts (e.g., playing the role of a "blind person") than in societies where disabilities are often primary criteria for defining roles.

Persons with congenital conditions that decrease their desirability as spouses, or impair normal functioning, are in a more vulnerable position. They may be deprived of the opportunity of ever becoming, in Rotuman terms, a fully competent adult. In the final analysis, however, the ways in which people with disabilities are treated on Rotuma depends far

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❖ The Connection of Ability and Disability on a Subsistence Atoll

Patrick O'Brien, Open Sea Foundation, San Diego, California

On Faliuw, a small atoll in the western Pacific, the integration of people with disabilities with non-disabled others reflects an encompassing system, an ecology, where individuals are not segregated or polarized based solely upon able or disabled states. Rather, there is an acceptance of the alteration of power associated with physical, mental or performance differences, and a personal inability is socially adjusted. A balance between varied states promotes the sustainability and viability of the atoll system. There is an acceptance among abilities and a social regrouping around extreme cases. This regrouping overcomes the incapacities of the physical or mental disability while not necessarily segregating the person with a disability as either deviant or not of value. On an island 1/10 of a square mile in size, 7 feet above sea level, populated with 150 individuals of shared history and shared future, the relationships between ability and disability are not dichotomized.

This paper uses a health ecology approach to consider individual abilities, or the lack thereof, within an atoll system. This perspective includes a symbolic interactionist focus and also emphasizes cognitive and productive domains within an ecological niche. Isolated atolls, with their well-defined tidal parameters, reliance upon interactive social alliances and maintenance of longitudinal relationships, are appropriate settings for such an interactive approach in considering abilities and disabilities.

On Faliuw, to be disabled is to be of questionable productive power. The process of socializing disabilities and the individual behaviors affected by a disability can be portrayed against a dimension of economic or productive power. The common term for a disabled person is *mu'ash er tikeid*. *Mu'ash* is the polite address and *tikeid* is "not strong." More specific to a physical disability is *hurfabo*, which can mean either cripple, not normal or poor as, to be not normal or physically incapacitated on this subsistence island is to be poor. The associated emotional reaction to someone who is viewed as poor is to feel sympathy and responsibility for that person, *fago*. This emotion of compassion generates a complex of supportive behaviors. The intensity of support varies in degree depending on family/clan relationships, but extends, nonetheless, to every other person of the island. The idealized cognitive model on Faliuw promotes and reinforces

emotions and behaviors which assimilate the able and the disabled, the proficient and the less skilled, the powerful and the weak into a sustainable and balanced ecological and social system.

Thus, the perception of disability on Faliuw proceeds from a cultural and cognitive environment which emphasizes dependency, closeness, unity and belonging. The island polity competes in the environment as an interactive unit, inclusive of both able and disabled, strong and weak. Disabilities are assigned importance in relation to both their perceived etiology and their effect on island sustainability. The response to disabilities is one of habitation rather than rehabilitation. The nature of Faliuw perceptions and reactions to abilities and disabilities is important, not merely for the implementation of disability-related services and care programs to the populations of the islands, but also for the equally, or even more important, reason of carrying such perceptions of unity and interdependence back from the open sea periphery to the Western health center.

Guam's Pacific Daily News highlighted provisions of the new Americans With Disabilities Act. For Pat Botten, one of the founders of the Western Pacific Association for the Disabled, the wait had been far too long. Anticipating the passage of the act was like "waiting to gain status as a human being."

❖ Disability in the Western Pacific: Perspectives from Guam

Rebecca A. Stephenson, University of Guam

Recent events in the American territory of Guam have called the attention of the general public to the place of the disabled in Guam society. Persons who are disabled are becoming more vocal as well as visible on Guam, but their place in the indigenous Chamorro society requires careful study, and the interests of people with disabilities generally need to be addressed in more effective ways than in the past.

A consideration of the Chamorro language indicates words which describe disabling conditions: *yamak* (disabled; to break, destroy, impair, disable); *a'pe, pire', ~E~* (harelip); *ti naturat* (abnormal, not natural); *makabebi* (cripple); *kobu, manko* (crippled; to amputate, to cut off); *bachet* (blind, cannot see); *tangnga* (deaf, cannot hear); *tinangnga* (deafness, hard of hearing); *taktamunda, tattamudu, uda* (f), *udu* (m) (dumb; stutterer; stupid, don't think); and for crazy there are *a'baba* (*baba* means bad), *o'duko, 'atmariao* (has no care for what anybody thinks), *kaduka* (f), *kaduku* (m) *kuka', loka, loku* (crazy, as slang is a'langa'). Shades of meaning in an evaluative sense are attached to a number of the Chamorro words.

Recognition of disabilities may be found in certain family names on Guam. These are locally derived descriptive names for particular extended families, e.g., *Cojo* [lame, person with a limp]. Persons on Guam affected with *litico* or *bodig*, local neuromuscular diseases of long known temporal dimensions, represent another category of the disabled. Some 100 patients with neurological disorders receive assistance from the Guam Lytigo and Bodig Association. Patients are given items such as wheelchairs, commodes, shower chairs, hydraulic hospital beds, and adult diapers from the organization. Yet, people with disabilities are sometimes hidden at home and disregarded. Factors of shame may be involved. Shame (*mamah'lao*) is a collective concept in the Chamorro language that can assign blame to entire kinship groups for the situation of a single individual. Guam's predominantly Catholic sociocultural orientation may be significant in the analysis. In Chamorro culture, it may be felt that a disabled person is, so to speak, given to a family as their particular "cross to bear."

On January 29, 1992, Guam's *Pacific Daily News* highlighted provisions of the new *Americans With Disabilities Act*. For Pat Botten, one of the founders of the Western Pacific Association for the Disabled, the wait had been far too long. Anticipating the passage of the act was like "waiting to gain status as a human being," she said. In assessing Guam's compliance, she pointed out that well meaning businesses, for example, often place ramps and other facilities in places impossible for a disabled person to reach. In a wheelchair herself, Botten notes: "Businesses go to hell with good intentions." In October 1991, a range of activities occurred on Guam for Disabilities Awareness Month. Owing to recent rapid socioeconomic development and labor shortages, new opportunities in gainful employment are opening up for people with disabilities. Daniel Naputi, the first Chamorro to graduate from

Gallaudet University, Washington, D.C., is an example. "I never thought that I would be the first, " says Naputi. "Hearing people thought I would not be successful. But I did it, and I have my degree now in personnel management. We, the deaf, are the same as everybody else."

The University of Guam hosted a workshop entitled "Delivery of Services to Disabled Persons" on October 21-23,1991. The press gave much attention to the fact that the chosen venue, the modern Top 'O the Mar, did not have wheelchair accessible bathrooms. Yoichi Rengiil, a co-organizer of the workshop, pointed out that he inquired of Top 'O the Mar whether it was accessible for disabled persons and had received an affirmative response. Rengiil noted that "accessibility" means different things to different people. The University of Guam workshop concluded that Guam clearly lags in accommodating individuals with disabilities. The international Pacific Star Hotel was acknowledged for its poolside chairlift to assist people with disabilities entering and exiting the swimming pool. But, a survey of eight Government of Guam buildings conducted by workshop participants indicated numerous violations. At Guam Memorial Hospital, for example, in the older section of the hospital, many of the restrooms are not accessible, doors are heavy and awkward, elevators are often out of order, and the pharmacy is not accessible.

Looking ahead, the involvement of persons with disability themselves in their advancement on Guam seems likely to grow. The situation of Daniel Naputi again comes to mind: "I want to teach sign language here on Guam," says Naputi, who spoke on accommodations for disabled tourists at a recent workshop at Guam Community College. "I want to live on Guam and help people." As elsewhere in the Pacific, disability self-help is under development.

❖ *Disability and Rehabilitation in Cross-Cultural Perspective: A View From New Zealand*

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Physical and mental impairments are universally found among people in all societies. Disability or functional limitation resulting from impairment is subject to cultural interpretations, which can and do depend upon such factors as context, socio-historical time, and perspectives of the observers. Disability and its definition accordingly vary from society to society. What is a disability in one society may or may not be a disability in another, although every society seems to recognize disabilities of some sort. By working cross-culturally, we can note differences in what is regarded as a disability, and thereby become aware of the cultural themes operating, the contexts in which disability appears, the variations between historical and contemporary times, and the impact of observers—particularly those involved in monitoring and alleviating or treating disability as rehabilitation workers.

People in New Zealand, for example, regard accident created disability markedly differently from illness induced disability. Substantial differences in the benefits available, even when the resulting disability is similar, demonstrate this situation. The story of why these differences occurred, and why they persist, reveals a unique New Zealand history and culture.

In another example from the same geographical area, the indigenous Maori in New Zealand regard the common Western goal of rehabilitation, that is, independence, as strange or even "sick." They see interdependence and the ability to carry out participation in social groupings as a proper and suitable goal. With the emphasis on strong family connections, and an interconnected personal identity or self, independence is not a desirable, or even acceptable, objective. These, and other examples from New Zealand, demonstrate that cultures, contexts, times, and the eye of the beholder all play a significant role in determining disability.

As observers, assessors, and managers of disability, rehabilitation professionals and workers hold a key role in disability related definitions, classifications, interpretations, and interventions. Increasingly, however, people with disabilities are taking a greater part. New moves towards advocacy, networking, and empowering in New Zealand are leading views from the past towards new and different paths. Still, but possibly not

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forever, studies of disability depend upon rehabilitation workers and, particularly in "less developed" societies, the carers, including family members.

Rehabilitation workers operate from a wide variety of models, under a range of policies in a plethora of agencies, and from different disciplinary backgrounds. These differences result in wide variation in determining and defining disability. Disability is not entirely in the eye of the beholder, but a good part of it is, and therefore, rehabilitation professionals and carers (including family) must constitute an integral part of cross-cultural research on disability.

❖ *Diabetes Management: A Polynesian Perspective*

Judith C. Barker
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Good self-management of diabetes is essential for reducing long-term health consequences and for preventing disability. Successful self-management is not a simple task, however. This paper examines some reasons why self-management is especially difficult for Polynesians.

About 75% of all diabetics have non-insulin dependent diabetes mellitus (NIDDM). In most populations, NIDDM is primarily a disorder of older adults and females. In the United States, around 3% of the general population has diabetes. The prevalence of NIDDM in Pacific populations varies widely, between 3% and 18%, with rates above 5% being associated with more modernized or urbanized populations.

Of all Pacific populations, Samoans have been the most studied with respect to NIDDM. It affects the middle-aged as often as older Samoans. Diabetes mortality rates are high, and secondary retinopathy and nephropathy common. Lack of control of hyperglycemia and failure to comply with medication regimens are common problems.

Obesity, a noted feature of Polynesian populations, is linked to central fat deposition, relatively lower activity levels, higher caloric intakes, more modern life-styles, greater psychosocial stresses, and impaired glucose tolerance. Self-management of NIDDM is a constant, highly complex, and demanding task. Important components include: regular exercise, achievement and maintenance of normal weight, and stress management, along with regular monitoring of blood sugar levels, and preventive health care check-ups, especially of eyes, feet, and teeth. Diet is the key element.

For the diabetic eating is a far from simple activity. It involves monitoring daily caloric intake, minimizing the ingestion of simple sugars and fats, and maximizing the intake of vegetables, fruits, and grains containing complex carbohydrates. It also involves eating smaller, more frequent meals with the largest meal at midday, eating on a more rigid schedule without skipping meals, and adjusting caloric intake to match activity level. These quite formidable requirements call for considerable knowledge, constant self-monitoring and regulation, careful time and household management, and an ability to put one's own health needs before familial or social needs. Polynesian cultural values make these requirements difficult to achieve.

Precise attention to time is not a feature of Pacific life. This makes the regular scheduling of meals or snacks difficult. Sharing food with family and strangers is a central cultural imperative. To not eat when invited to do so, especially if a guest, is a very serious breach of the social fabric which is strongly negatively sanctioned. Being physically imposing, tall, strong, muscular or fat, is a sign of rank, wealth and health, even of being in supernatural favor. Obesity is not as stigmatized as in Western societies.

The traditional Samoan diet matches diabetic needs quite well. Although new Western foods, including "fast foods," are powerful symbols of modernity, they tend to be higher in fat, contain simple sugars and less complex carbohydrates; they are usually added to traditional foods not substituted for them. This leads to over-nutrition, and not just for diabetics. Over-nutrition and under-activity go hand-in-hand, especially in more urban populations and among those with sedentary occupations.

Successful self-management of NIDDM (or other chronic diseases) necessitates self-observation, self-evaluation, and self-regulation which require the subjugation of a social- or group-orientation to the self This is the exact reverse of the psychological pattern typical of Polynesian societies which traditionally emphasize strong social and familial orientations. Although they engage in self-observation, Polynesians, especially those in more traditional or rural areas, do less self-evaluation or self-regulation.

Reference to poor future outcomes will probably fail to motivate a Polynesian diabetic to good self care. One's present behavior towards family or wider social group matters more than any remote future possibility concerning the self. Stress exacerbates diabetes. Family-oriented stress events receive stronger reactions than self-oriented events. Moreover, Polynesians are somewhat fatalistic, accepting all outcomes, good or bad, with a degree of equanimity.

In other populations, health beliefs about NIDDM and its possible future consequences are important to successful self-management of NIDDM. The belief structures of Polynesian (and other Pacific) societies with respect to "new" disorders are essentially unknown. In the next decade or so, Pacific nations will face potentially crushing burdens as more people develop diabetes and diabetes-related disabilities. It is imperative to assist Pacific Islanders to manage this disabling disease. Unless prevention and education efforts are cognizant of and sensitive to sociocultural issues, many such efforts will not be successful.

❖ *Discussion and Comments*

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The anthropological study of disability is a growing area of research interest. Until relatively recently, most work has focused on developed countries, with relatively little information from the developing world. The 1981 UN International Year of Disabled Persons stimulated increasing interest among anthropologists and policymakers in issues of disability in developing countries. Yet there is still very little information about the social contexts in which people with disabilities live their lives, so this collection of information from the Pacific is particularly valuable.

The first point to be made from this collection of papers is that researchers working in developing countries need to be very wary of issues of language and thinking about disability. The frameworks for understanding impairment, disability and handicap that have been so fruitful in the West, may not be as useful in small-scale societies such as those in the Pacific. It appears that in most of these communities, a general category of disability does not exist, that people are blind or crippled or deaf, but not "disabled." Disability is a sociopolitical concept, one that may not fit in the understandings of people in many small-scale societies.

Further, attention to the specific vocabulary that people use to describe impairments may tell us much about their understandings of those impairments and the social contexts and consequences of impairment. Adoption of Western labels for these impairments will result in a significant loss of information.

Pacific societies are undergoing profound changes. The transition from infectious to chronic diseases as major causes of mortality and morbidity is a very profound change, one that will have major consequences for health care services in these countries. A second major change is out-migration. Since many of the people who leave these countries for New Zealand, Australia, or the US are young adults, the demographic structure of many of Pacific societies is undergoing dramatic changes—with greatly increasing percentages of young children, the elderly, and disabled adults. The third major change that is not yet well documented is the changing nature of injury. Causes of injury are increasingly related to motor vehicles and accidents. This has significant consequences for the nature of disability in these communities.

One of the most important points made by these papers is the importance of societal scale in determining the consequences of disability... in a small-scale society that has less emphasis on a cash economy, the individual might occupy many productive social roles so that a physical or mental impairment that interferes with one of those roles may not be as devastating as in a large-scale, money economy...

One of the most important points made by these papers is the importance of societal scale in determining the consequences of disability. Some of the societies discussed in this collection are extremely small. Since most of the literature on disability comes from Western, industrialized countries, data from small-scale societies, such as most Pacific societies, are especially valuable. One suggestion from these papers is that in a small-scale society that has less emphasis on a cash economy, the individual might occupy many productive social roles so that a physical or mental impairment that interferes with one of those roles may not be as devastating as in a large-scale, money economy where employment is the primary source of a person's value.

A second factor in a small-scale society is the possibility of intimate shared history with most members of the community. The inclusion or exclusion of individuals from the group is probably a much different process than in large-scale, bureaucratized societies with many impersonal relationships.

Finally, many of the descriptions of disability presented in these papers suggest that disability is an instance of disruption of the body and potential loss of personhood or adulthood. The management of disability may focus more on minimizing loss of adult status than on meeting social obligations. The cultural analysis of disability will benefit by looking at disability in this broader context of what it means to be an adult or a person.

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The purpose of the IEEIR is to provide opportunities for the U. S. disability community to become more aware of developments in Asia, the Pacific, and Africa through fellowships awarded to U.S. disability specialists, publications prepared by foreign experts, and through conferences and meetings. **Interchange** is another way of sharing information about the IEEIR on international developments. For more about the Project, write or call:

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Project Information Since 1978, The IEEIR has funded over 175 fellowships for U.S. disability specialists and advocates to conduct brief study-visits in other countries. Also, the project has published 52 monographs written by foreign authors and participated in numerous conferences and meetings. The project currently disseminates over 60 fellowship report and monograph titles, as well as this newsletter, *Interchange*, published three to four times a year. For detailed information on what is currently available from the project and how to obtain it, write or call.. Because this current three year project will be concluded September 1993, we are no longer making Fellowship awards.

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